

reviews

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Doctors on the Edge: General Practitioners, Health and Learning in the Inner-City

Linden West



Free Association Books,
£16.95, pp 230
ISBN 1 853435 24 4

Rating: ★

In case you didn't know, there are plenty of problems in inner city general practice these days. Morale is rock bottom, bureaucracy is burgeoning, and patients are baying for doctors' blood. Some people say it's on the verge of collapse, but, in my experience, things that are on "the

verge of collapse" are usually still standing when you come back 20 years later.

This book, based on four years of interviews with 25 inner city GPs, gives us a flavour of what it's like out there on the front line. It is a splendid example of narrative-based research, full of the raw and gritty stories of a diverse group of doctors who are trying, usually with great difficulty, to keep their heads above the rising waters of patient demand, organisational change, and personal crises. Some of them, as the title implies, are truly "on the edge." Doctors like Daniel Cohen (the names have been changed), who thinks general practice is "like swimming along an endless river and trying to have intelligent conversations while you are swimming." Or Dr Ambi, whose eldest daughter said to him: "Daddy, you are going to lose me soon, because you don't sit and talk to me." No randomised controlled trial could ever give us this kind of picture of life in general practice.

But it's not enough simply to transcribe the interviews on to the pages of a book. An author also has a duty to draw things together. It is his job to make sense of it all,

and it is here that Linden West's contribution is less good than that of his interviewees. His commentaries are so full of jargon that at times I wondered if I had mistakenly wandered into the omnibus edition of "Pseud's Corner." Chapter two is called "A gendered cultural psychology in transitional times." West talks about "loving and reciprocal relationships as a basis for sustaining the ontological project of the self." He reminds us (in case we had forgotten) of "a growing 'resacralisation' in contemporary life, both in relationship to the natural world and in our relations with each other."

It is impossible for an author to write a book that does not reveal a great deal about himself, and West is not afraid to tell us where he is coming from. "I was," he writes, "during the time of the research, undergoing major changes in my life and renegotiating aspects of my identity." He calls his style of research "auto/biographical." *Doctors on the Edge* would have benefited from less emphasis on the "auto" and more on the "biographical."

Fred Kavalier *primary care geneticist,
Guy's Hospital, London*

How to be a Good Enough GP: Surviving and Thriving in the New Primary Care Organisations

Gerhard Wilke with Simon Freeman



Radcliffe Medical Press,
£19.95, pp 224
ISBN 1 85775 358 5

Rating: ★★★

but rather than oppose we shall come to listen, learn, digest, and finally accept.

Accepting change without experiencing permanent grief will require a cultural shift—one that will only come, Gerhard Wilke argues, with the end of the overidealised doctor-patient relationship. Wilke's highly accessible discussion about change comes charged with the wearisome wisdom of one who has observed at first hand the chronic bereavement that GPs have been struggling with since the 1990 "New Contract."

Since then, of course, there has been fundholding, there have been primary care groups, and now we are involved in setting up primary care trusts.

Recent history, therefore, suggests that change is inevitable, leaving little room for nostalgia. Wilke advises us that if we are to survive in general practice we must relinquish any yearning for the lost world of an NHS that is free of politics and resource management. We must also be aggressive enough to formulate our own needs and negotiate for them. Survival and recreation in the current context of continuous change and improvement, says Wilke, depend on whether the doctor can learn that self care is the best way to improve patient care.

But as with the gestation of all publications, even Wilke's book has not kept up with the pace of change. It was conceived at the time when primary care groups were just beginning to emerge, but most of us have already moved on.

Despite this, *How to be a Good Enough GP* is a useful and thought provoking read for anyone interested in relationships and organisations. Cut to the section on Wilke's observations of the dynamics rife in a single practice, and it becomes abundantly clear that what does—or does not—work for a small group has much relevance for larger organisations. The same conscious and unconscious processes apply. If you are now actively involved in primary care trusts, look at what happens in your own practice, and take note.

Abi Berger *BMJ*

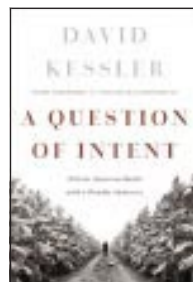
One day GPs will no longer be surprised or thrown off track by political change. One day we will come to embrace change with the same guarded conviction we show when we learn about new drugs. We may pause and resist,

*Items reviewed are rated on a 4 star scale
(4=excellent)*

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A Question of Intent: A Great American Battle with a Deadly Industry

David Kessler



Public Affairs Press, £19.99,
492 pages
ISBN 1 891620 80 0

Rating: ★★★

David Kessler, United States Food and Drug Administration commissioner from 1990 to 1997, clearly changed the world in which the tobacco industry does business. In this timely memoir, he describes how the FDA's historic decision to move against tobacco hinged on proving that tobacco companies designed their products with the intent to get consumers addicted.

The need to demonstrate such intent, an artefact of American regulatory law, explains why the administration sought to regulate tobacco products as "nicotine delivery devices." Ultimately the Supreme Court ruled narrowly that the FDA lacked the legal authority to do so. As Kessler laments, tobacco remains largely unregulated for health and safety as the new millennium begins.

Still, the FDA's investigation, which exposed the tobacco industry's manufacturing practices and targeting of underage consumers, helped change the way in which society views cigarettes. It did so by turning

public attention to the bad conduct of the industry, which marked a departure from the government's customarily narrow focus on the health effects of smoking. Kessler's investigators obtained previously secret industry documents that described ways to control nicotine delivery, which Kessler highlighted in televised congressional hearings. The administration's probe also benefited from the simultaneous pursuit by state attorneys general of legal actions against the industry, which forced disclosure of millions of pages of industry memos and reports, although Kessler's memoir downplays this.

Kessler's memoir is a well crafted work that reflects a passion for detail. Yet it contains a remarkable hidden flaw. His version of the forces that propelled him to strike at tobacco omits critically important information. Only a handful of people, including Kessler and this reviewer, know this information.

Kessler tells of "Deep Cough," a cigarette company insider who briefed the FDA on the industry's manipulation of nicotine. Yet he pointedly fails to acknowledge that without the information that Deep Cough imparted, the FDA would not have been able to launch its investigation. He also omits that this reviewer, not others, brought Deep Cough to the agency after spending three years nurturing this pioneering yet terrified informant.

As told in journalist Dan Zegart's *Civil Warriors: The Legal Siege on the Tobacco Industry* (Delacorte Press, 2000), which quotes internal FDA records, Deep Cough gave the FDA its first information about the tobacco industry's manipulation of nicotine. Kessler knew next to nothing about the subject until just six weeks before he announced that, on the basis of such information, the FDA would consider regulating cigarettes. Kessler



GENE J. PUSKAS/AP PHOTOS

Kessler: changed society's view of tobacco

does not mention that without Deep Cough and the impetus provided by an investigation into nicotine manipulation begun by the ABC News programme *Day One* a year earlier than the FDA's probe, he lacked the tools and resolve to act.

Perhaps he negates these central events because their inclusion would muddy a storyline that makes him the only important initiator of a great regulatory crusade against tobacco. While this shortchanges history, the greater wrong is that it annuls the role played by activism and investigative journalism in launching major social change.

Clifford Douglas *president, Tobacco Control Law and Policy Consulting, Ann Arbor, Michigan*

The Tragedy of Childbed Fever

Irvine Loudon



Oxford University Press, £40,
pp 250
ISBN 0 19 820499 X

Rating: ★★★

This is an extended monograph about a once terrifying infection, whose reality is now recalled only by those who lived in the pre-antibiotic era. Its whole history is covered—early beliefs about the nature of the disease, the importance of midwives, the epidemics within the death

houses that lying-in hospitals became, the succession of famous names who contributed to the understanding of the infection, and the various and often angry opinions about aetiology and management. The discovery of bacteria in the late 19th century, plus the discovery of antiseptics by Lister, led in the 20th century to the control of the disease.

Loudon states: "I have tried to write for readers with no special knowledge of medical and bacteriological matters," and for practical purposes he has succeeded. The dramatic opening story of the death of a patient soon after the birth of her second child (though the retained placenta made this case unusual) tells us what puerperal sepsis meant to her family and to the newborn baby left behind.

All the ingredients for a first class monograph are here: the early clinical association with another disease, erysipelas, leads well to the endgame, when the streptococcus was identified, isolated, and its ferocity overcame.

The hint that the "microbe en chapelet" was the cause introduces us to Louis Pasteur and some lesser known contemporaries and enemies: Dr Gordon of Aberdeen and Banchory; Dr Brown of Coventry in 1874 and the subsequent *BMJ* leader that looks ahead, perhaps, to today's pandemic of litigation; Oliver Wendell Holmes; Domagk's work on Prontosil red.

Reading the portraits of doctors is pleasant—one can skip the sometimes overdone accounts of so many cases and figures, but don't miss the reassessment of the life and worth of Semmelweis. The revisionist historian is too often a socially correct one, seeking journalistic novelty, but Loudon is the true academic, and medically qualified historian colleagues will enjoy his account. I recommend it to them especially.

John S G Blair *vice president, International Society for the History of Medicine, and honorary reader, history of medicine, University of St Andrews*

PERSONAL VIEWS

Consent to cancer registration—an unnecessary burden

Imagine this scenario. Mrs "I-Could-Be-Anybody" enters the consulting room with husband and daughter in tow. Consultant, looking and feeling uncomfortable, says: "Unfortunately, the biopsy report confirms our suspicions and fears that you have a cancer in the throat. The best treatment for this will be what we call a pharyngolaryngectomy, which means taking out part of the gullet and all of the voice box, and filling the defect with a length of your small bowel. We will also take out the lymph nodes from one side of your neck, and we might have to follow this up with radiotherapy over six to seven weeks. You won't be able to speak properly again, and you may have to have a machine to hold against your neck so that you can have a voice like a Dalek with which to communicate. Your swallowing won't be particularly easy either. I regret to say that your chances of surviving the operation and the cancer are probably no more than 20% at best. By the way, would you mind if we sent your details to the local cancer registry?"

Mrs I-Could-Be-Anybody is feeling faint and nauseous, husband and daughter are in tears, and none of them has taken much in

since the word cancer was mentioned. They care an awful lot about whether there is a future and what it might hold, and they don't care a damn whether or not data is sent to the cancer registry—they really have more important things to think about.

Do I exaggerate? Possibly, but not much. The General Medical Council's pronouncements on confidentiality have sent shock waves through the world of cancer surveillance due to the GMC's insistence on informed consent from each individual patient for the transfer of data to cancer registries (*BMJ* 2000;321:849). Not only do most clinicians "at the sharp end" know that this is simply unworkable, but the GMC itself

has the cheek to acknowledge that "The refusal rate would be negligible." So, we are supposed to put into action bureaucratic means of policing whether patients have given their consent, ensuring that the records of those who have not (or

more likely have never been asked) are not sent to the registry. We will have to make special arrangements for minors, mentally disordered people, and those for whom English is not their first language, and for those who, for other reasons, have to be specially catered for to ensure they understand

the nature and purpose of cancer registration. By these means we will effectively wreck legitimate, high quality, and credible epidemiological research, together with the hopes of those of us who believed that cancer registries could support outcome audits and the monitoring of clinical standards by collecting an extended and more clinically relevant data set.

Is this an acceptable price to pay to protect the rights of patients who we know are unlikely to regard data held about them on a cancer registry as a threat? Is it so difficult to accept that it would be perfectly adequate simply to provide patients with a statement among the general information given to them, to the effect that data is normally sent to an appropriate disease register unless they choose to opt out? Posters in outpatient waiting rooms could reinforce this message. There would be no need for a doctor to remember to give an unnecessary explanation of the purpose of cancer registration to a patient whose concerns lie elsewhere; no need for cancer registration consent forms or "consent policemen"; no need to undermine the public health responsibilities of cancer registries, and no need to deny future generations of cancer patients the cancer controlling role of those registries. Cancer registries collect data on some non-cancerous tumours and not on all cancers (skin cancers are excluded, for example)—try explaining that to patients.

The GMC says these patients are going to consent anyway; but for the tiny minority who might not, the registries, clinicians, and cancer patients all have to be inconvenienced. I don't think this is a price worth paying; the cure is far worse than the disease. Cancer patients often accept considerable risks to maximise benefits, but they are more likely to regard data held on a cancer registry as a real benefit to society rather than as a risk to themselves.

The GMC's pursuit of political correctness is a sad response to the fact that many of today's standards are shaped by an unrepresentative, vociferous minority that has replaced unspoken trust with a culture of blame. Giving hospitals until October 2001 to prepare for the demands of new confidentiality guidance in relation to cancer registration should not be seen as generous. It is the underlying principle that is fundamentally flawed, and no amount of time will alter that.

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We will effectively wreck legitimate epidemiological research



WEBSITE
OF THE
WEEK

Tobacco money An article in this week's *BMJ* debates whether or not Nottingham University should give back £3.8m (\$5.3m) in sponsorship from British American Tobacco (p 1118). In giving away money to support useful and blameless activities tobacco companies believe—and no doubt they have checked with focus groups—that their generosity helps to create positive feelings about their other activities in the public mind. To find out more about the message they are trying to get across, it is worth having a look at their websites.

Before you click on Philip Morris (www.philipmorrisusa.com), British American Tobacco (www.bat.com), or R J Reynolds (www.rjrt.com), take a guess at what a tobacco company website might look like. Promotional perhaps, seeking to win customers from the opposition with subliminal suggestions; strong on the life-enhancing properties of the brand, weak on its life-shortening properties. The surprise is how frank these guys are. They give it to you straight: smoking is bad for you. Teenagers shouldn't start. If you're a smoker who wants to quit, you should. To prove that they mean what they say, BAT has a link to www.givingupsmoking.co.uk and R J Reynolds won't even let you on to the website about its new cigarette (www.eclipse.rjrt.com) until you prove you are over 21 years old.

The dominating theme is that smoking is about intelligent, fully informed, adult choice. If you want to deny yourself a lifetime of pleasure to improve your mortality, that's up to you. Don't interfere with the habits of those who have decided to go the other way. It is at least a coherent argument. Indeed, it is probably the only coherent argument. But like the dog that famously didn't bark at night, the most significant thing about these sites is not what they give you but what they leave out. The World Health Organization estimates that 75% of tobacco related deaths over the next 20 years will be in the developing world. The R J Reynolds site is so big that it has its own search engine, but typing in "developing world" produced not a single hit.

Christopher Martyn
BMJ
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Internet therapy

Diagnosing an untreatable illness is a bad moment, and explaining it to a patient is even worse. This experience is unusual for Italian doctors, who usually prefer to tell the patient's partner or relatives. It is then up to them to decide whether or not to let the patient know about his or her fate.

This is not ethical practice, nor is it right to treat patients as children, but it is common in Italy, where we are not taught how to deal with patients or how to give bad news. Our Latin culture and famous sentimental attitude still reject the idea of an inevitable death. We prefer to ignore it and pretend there will be a happy ending.

So it was unusual for me to explain to my patient and her husband that she was suffering from a fatal degenerative disease of the nervous system and that the only useful drug would probably only delay her death and prolong the agony for her and her family. I was compassionate but precise and sincere and suggested how they could prepare themselves for the remaining few years.

I saw the couple again two years later. The patient had seen several other neurologists, more authoritative but less direct than me. She was already connected to a ventilator, being fed with a tube, her body as well as her life almost destroyed. They told me that no one had clearly explained what was going on—or were they preferring to ignore the reality?

It was then that the patient's husband, browsing on the internet, found "The therapy" for her disease. In a well written and meticulous way, it stated that "The therapy" had already saved the life of its inventor, and for about \$1000 (£625) every patient could be treated in the same way and be healed. The whole thing sounded very convincing to lay people, although it was clearly stated that "The therapy" was not yet recognised by the US Food and Drug Administration.

They asked me to try this last magic. At first I was quite angry. I had spent years

studying neurology, and now an electronic swindler, with two well written lies, was considered more reliable than me. Why not a pilgrimage to Lourdes? The odds were the same, but "The therapy" advertised on the internet and offering a kind of machine had a more scientific appeal.

I discussed with colleagues the unethical practice of making money out of patients' desperation. I thought that these miracle cures should not be available on the electronic highway—the symbol of progress and science—but someone reminded me that you can buy almost anything on the internet, good or bad. Why not the hope of escaping from a certain death?

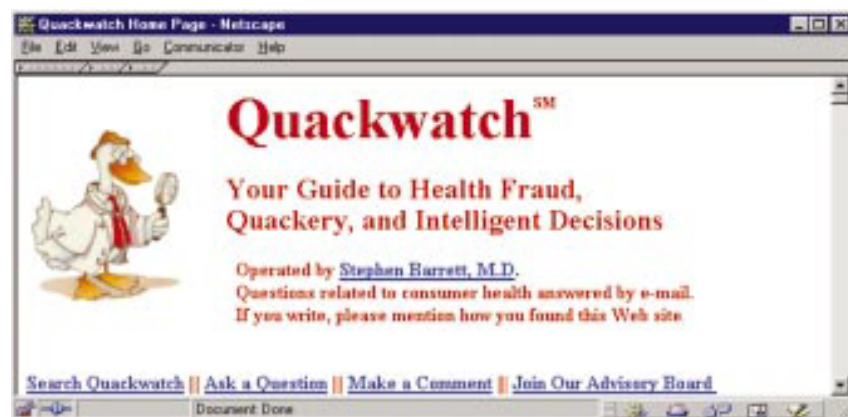
I wasted a lot of time trying to convince the family that the therapy was really an expensive placebo and that to rely on it would lead to useless and stressful suffering. The couple insisted, and I agreed to play the part of apprentice wizard using "The therapy." I set up the whole procedure and trained the nurses and the therapists, instructing them to act as if it was a real treatment.

I feel very uncomfortable in this role, cheating on the woman with daily visits in which I prepare "The therapy" for her. But the tired smile on her lips and her insistence on feeling better (a good placebo effect, I admit) win me over and I keep on with the play acting, inviting her to think positively and let the force of nature enter her as is suggested in the rigorous instructions. She is dying happy and hopeful, and that is what her family wants. But I think that she knows the true situation, and that she, like me, is playing a part, trying to cheat on herself to make her family more comfortable.

After all, it is not always necessary to tell the truth, nor is it useful if the patient does not want to listen and when the internet offers a last unreasonable hope to die with.

This paper is dedicated to my friend and mentor, Professor Giuseppe Caruso.

Claudio Crisci *chief of the department of neuro-rehabilitation, medical centre of Telese Terme, Italy*



Monitoring health fraud: but does internet quackery offer patients hope?

SOUNDINGS

Teaching English as a dead language

Many years ago I learned English. I don't mean mother's-knee English—although I'm told that I learned that quite quickly, and grew a vocabulary from the Sunday broadsheets at an age that I'd rather keep to myself—I mean learning proper English.

I was taught for five years by a man who took it all very seriously. He had even written a book. He would plan the week's work on a Monday. ("Monday, my book. Tuesday, Keats. Wednesday, my book. Thursday, Shakespeare. Friday. Hmm. My book.") We spent a lot of time with his book: learning figures of speech (from aposiopesis to zeugma, as I recall); practising such arts as essay and précis writing; and working through exercises that consisted of dismantling increasingly complicated sentences into their basic grammatical elements—a process known as general analysis.

I rather enjoyed it. The rules were complex, but quite clear once you'd got them; and the satisfaction of taking apart in detail a 300-word sentence by Thomas Babington Macaulay is one that only devotees can know. Now, I suspect, there are few left.

Not long after I left school, my teacher died—suddenly at a second year Christmas dance, forever spoiling the St Bernard's waltz for some poor girl—and 40 years on there are, I am told, no surviving teachers remotely resembling him.

I still think of him from time to time. He stood as a ghostly presence at my shoulder through many hundreds of hours of writing. When I joined an academic department and disagreed with its head about an arcane point of grammar, I was delighted to discover that he too had been taught—at another school and before the war—by the late great author of *Interpretation and Language Exercises*, who is still not far off as I write this now.

Even in his time he was old fashioned. I could not have made that judgment then, because there was no one to compare him with. But once, I happened to meet at a party a retired school inspector whose subject was English. We talked a bit and I mentioned my late teacher. "Him." He clutched his brow and groaned. "That man held up the progress of teaching English in Scotland for 25 years . . . Singlehandedly." Suddenly, I felt even more privileged than before.

Colin Douglas *doctor and novelist, Edinburgh*